

SCHOOL CARE PLAN

PUPIL INFORMATION

SURNAME: _____ **Date of Birth:** _____

FIRST NAME: _____ **Male/Female** _____

MEDICAL CONDITION: Ectodermal Dysplasia

ALLERGIES: _____

SCHOOL: _____ **Year:** _____

Contact Information:

Mother's Name: _____ **Father's Name:** _____

Home Tel: _____ **Home Tel:** _____

Work Tel: _____ **Work Tel:** _____

Mobile Tel: _____ **Mobile Tel:** _____

Email: _____ **Email:** _____

ADDRESS: _____

Authorised Emergency/Alternate Contacts:

1. **Name:** _____ **Relation to child:** _____
Home Tel: _____ **Mobile Tel:** _____

2. **Name:** _____ **Relation to child:** _____
Home Tel: _____ **Mobile Tel:** _____

3. **Name:** _____ **Relation to child:** _____
Home Tel: _____ **Mobile Tel:** _____

Doctor Information:

Name: _____

Address: _____

Tel No: _____

Key health professionals supporting this pupil:

The Ectodermal Dysplasia Society, Unit 1 Maida Vale Business Centre, Maida Vale Road, Cheltenham, Glos. GL53 7ER England Tel:
+44 (0) 1242 261332 Mobile: +44 (0) 7774 465712 www.edsociety.co.uk Email: info@edsociety.co.uk

Medical Condition: Ectodermal Dysplasia

Ectodermal Dysplasia is a rare genetic condition which affects an individual's temperature control, teeth, ears, eyes, skin, hair, nails, nasal passages, respiratory tract, muscles, behaviour, physical appearance, bowels, bladder, emotional wellbeing and a host of other challenges.

The arrangements set out in this document are intended to assist the child, their parents and the school in achieving the least possible disruption to school life and to maximise their education by making appropriate provision for their medical requirements.

A full explanation of how Ectodermal Dysplasia affects individuals is set out on Page 9 of this document. It is important all staff who care for this child must have read and understood this document.

Treatment Plan

All staff should be aware of the child's emergency plan. Specialist subject teachers (especially Sports teachers), supply/cover teachers, lunch room and playground staff should be fully informed. It is advisable to bring this School Care Plan to the attention of all new members of staff, supply teachers and assistants.

Lack of Temperature Control

Symptoms

Lack of concentration	Lethargy	Dreamy	Unco-Operative
Fidgeting	Disruptive	Clumsy	Badly Behaved
Nausea/Vomiting	Headache	Confusion	Dizziness

Treatment for overheating

- Ensure the child is next to a fan if available or arrange for one to be present
- Remove sweatshirt/jumper/cardigan
- Encourage the child to remove shoes/socks
- Put feet on a cold gel pack if available
- Encourage the child to sit down in a cool place or take them outside
- Encourage the child to drink cold water or juice
- Wet their hair, neck and T-shirt
- Use a spray water bottle on the arms, legs, face to cool the skin
- Place a cool wet cloth around their neck

Treatment for hyperthermia (cold)

- Ensure the child has appropriate clothing on
- Give a warm drink
- Warm slowly
- Do not rub hands or feet as this can be very painful

Take the child's temperature with an aural (ear) thermometer.

Always ensure the child is not seated next to a radiator in the winter months and not next to windows or in direct sunlight in the summer months. Ideally the child should always be seated next to a fan in the summer months and have access to a fan in the winter months if the central heating is on.

Note for Teachers: In an attempt to minimise bringing attention to the child's needs, it is recommended to move the whole class around if it is found necessary to reposition the child.

If the child is not co-operating, not cooling down or not warming up, please call their parents. However, please do not leave the child unattended and bear in mind if the child is overheating it can take 1-2 hours to cool down to a satisfactory level.

PLEASE REFER TO COVERING LETTER FOR THIS CARE PLAN, REGARDING A RAISE IN TEMPERATURE AND COVID-19

Routine School Treatment

Food

The staff in the school will take all reasonable steps to ensure that the child does not eat any food items unless they have been prepared/approved by their parents.

In particular, the child's parents will provide

- a suitable mid-morning snack
- a suitable packed lunch
- water or juice to drink throughout the day.

Off Site Activities

If there are any proposals which mean the child may leave the school site, prior discussions must be held between the school and the child's parents in order to agree appropriate provision and temperature management. Transport on a coach with no air conditioning in the warmer months is not acceptable. If transport provided by the school is not acceptable, the child's parents may be able to provide alternative transport.

Swimming

Care must be taken with regard to the child's temperature. They may request to stay in the water, rather than jump or dive in, this will be because they recognise it is warmer to stay in the water. Please honour their request; they will not be trying to get out of anything. Should they complain of being too cold they will need to dry and dress quickly and if possible, give a warm drink. If they become too cold, it can take 1-2 hours to warm up to a satisfactory level.

Sport/PE

The child must not be prevented from taking part in sport and should be actively encouraged to do so, but care must be taken regarding their temperature. If they are too hot or cold the child must be permitted to stop. The child must have a water/juice bottle with them at all times and if field sports it may help to have a bucket of water close by.

Break/Lunch Time

The child should be encouraged to go outside each day for fresh air. However, on hot/sunny days they must be encouraged to play in a shaded area and permitted to go back inside if they are struggling with their temperature, equally in the winter months' encouragement to go out but permission to return if they become too cold. It is not unusual for a child with ED to play outside in the winter without a coat; this is because they have become too warm in the classroom. However, they must take their coat outside ready to put on when they begin to get cold.

Student Information Card

In an attempt to minimise the amount of disruption during classes, to minimise the amount of attention brought to the child and to assist teachers and supply teachers, it is recommended that the school provide

the child with a Student Information Card. This card should give permissions such as leave blazer off, leave tie loose, leave classroom at any time to go to the cloakroom or to cool down, etc. See example below.


Student Information

Student Name: _____

Teacher: _____

Medical Issue: Lack of temperature control
Ectodermal Dysplasia

Please see permission overleaf



(Front)

Student Information

Permission at all times to:

- have a water bottle with me
- use the cloakroom
- remove my blazer/jumper/socks/tie
- have my shirt not tucked in and the top button undone

(Back)

Medication (to include storage arrangements)

- All medication required throughout the day to be applied/given by designated staff
- All medication is to be kept in school in a safe place
- The child’s parent must inform the school if any Calpol (paracetamol) has been given within 8 hours of attending school
- It is the parent’s responsibility to supply the medication and replace it if used or out of date
- Parents to be notified daily in writing when medication has been applied/given, the time and quantity

List of Medications:

Name of medicine:	Doseage:	Frequency:
Name of medicine:	Doseage:	Frequency:
Name of medicine:	Doseage:	Frequency:
Name of medicine:	Doseage:	Frequency:
Name of medicine:	Doseage:	Frequency:
Name of medicine:	Doseage:	Frequency:
Name of medicine:	Doseage:	Frequency:

Consent to Treatment

I agree to my child receiving medication and/or treatment as documented in the School Care Plan whilst in the care of education staff or transport staff.

I understand this is a service, which the school is not obliged to undertake if appropriate information has not been supplied.

I understand I am responsible for ensuring the appropriate medication is available to the school.

I confirm I am the parent/guardian for this child and I am able to give authority for the administration of the medication listed on page 8 of this document.

Signed: [Parent/Guardian]	Date:
Signed: (Head teacher/staff)	Date:
Signed: (SENCO/Nurse)	Date:

<p>Annual Review of Consent to Treatment</p> <p>The treatment/medicines prescribed for my child for use in school remain unchanged.</p> <p>Signed:..... Date:..... (Parent/Guardian)</p>

Agreement and Conclusion

There will be at least one meeting per term and one annual meeting to be held towards the end of each school year; any changes will be noted, the School Care Plan and IEP will be updated and circulated.

<i>On behalf of School:</i>	Date:
Signed: (Head teacher)	Date:
Signed: (SENCO/Nurse)	Date:
<i>Parents or Guardians of:</i>	Date:
Signed:	
Signed:	Date

Medication Record

Date	Pupil's name	Time	Name of medication	Dose given	Any reactions	Signature of staff	Print name

Ectodermal Dysplasia

One of the main factors of Hypohidrotic Ectodermal Dysplasia is the lack of temperature control. Children with this condition have an inability to sweat due to absent or reduced sweat glands and therefore overheat at any time of year, either from atmospheric temperatures or an impending infection. If these children are not cooled down, they become tired and lethargic and eventually this will lead to a fit or worse. Also, there can be problems in the winter months in maintaining adequate body temperature, i.e. they get too cold and have difficulty in warming up, should this happen the child will appear to be in a dream, not concentrating or listening.

One of the signs that the child's temperature is too high is their behaviour. They may become disruptive, disobedient, unco-operative or fractious. In many cases their skin temperature is absolutely no indication as to their internal core temperature. You cannot touch their skin and say they are cool or hot, some children have registered a temperature of 103f when their skin colour has been blue.

In an attempt to maximise the child's education, it is vital that all their medical needs are met to ensure their temperature is controlled.

Due to lack of temperature control the child will have difficulty in walking no more than a few yards in sunshine, on a warm or cold day and therefore has to be ferried everywhere in air-conditioned transport. Transportation is extremely difficult, as you will appreciate that most public transport does not have air conditioning and particularly in the summer months it would be extremely dangerous for them to travel on such transport.

The key sign that the child is overheating is a noticeable change in their behaviour. The teachers may recognise that they are in a dream and not listening or concentrating, this will possibly be the first sign that they are getting too warm. If they are not cooled down they will lose concentration which will mean that they are unable to follow the teaching in a lesson; they will then get bored, become disruptive, disobedient, unco-operative, fractious, lethargic and forgetful. Also there can be problems in the winter months in maintaining an adequate body temperature, i.e. they get too cold and have difficulty in warming up, should this happen the child will appear to be in a dream, not concentrating or listening. As a consequence, it may be that they should not go out to play but remain inside, although the child should be allowed out to play for a short period of time to ensure they have fresh air each day.

It is therefore extremely important to keep the child's temperature in check to maximise their concentration levels and thereby maximise their education. In the event that the child becomes too hot/cold they may take several hours to regain control of their temperature to a satisfactory level. This means that once they have begun to get warm/cold and are in a dream and not concentrating, they will lose at least the next hours' lessons if not more. The hotter they become the longer it will take them to return to a normal temperature. It is important for the child to be monitored throughout the day by someone who understands the condition, the signs to look for and who has been adequately trained.

Any child with this condition will refuse to go outside in the sunshine or insist on going to the cloakroom a million and one times a day. They are not being awkward or trying to get out of doing something, they are naturally trying to keep cool, either in the shade or by the use of water. They **must** be given access to water at all times.

As a consequence of the above aspects of their condition, they need constant monitoring with regard to the amount of clothes they are wearing, encouragement to wear clothes and encouragement to remove clothes when they start becoming hot or cold; and the application of wet clothing, sprays, or fans to cool them and clothing or heaters to warm them.

To assist the child in coping with the day to day management they must be provided with the use of cooling fans, water sprays, cold gel packs, drinking water/juice, etc. to ensure that their temperature does not rise to dangerous levels, or similarly fall to a level where they can fall into danger.

Misshaped Teeth

Many children are missing some or all of their teeth and those they have may be misshapen (pointed). The child may have their pointed teeth built up or wear upper and/or lower dentures. In addition to this they are lacking natural fluids in their mouth, throat and gullet due to a number of glands missing, consequently food easily lodges in their throat and leads to choking, they must avoid dry foods, have a drink available at all times and all mealtimes must be fully monitored.

Due to the absence of teeth they will required to have constant visits to either a local dentist or at a Dental Hospital for regular checks to ensure their gums are healthy and for any treatment such as adjustment to their dentures or new dentures made as the child grows.

Ear Infections

Recurrent ear infections are common, caused by the lack of mucus movement in the nasal passages, the build up of which causes infection to form in the Eustachian tube and thereby producing infection in the middle ear. The insertion of grommets is very common with ED children.

Eczema and Dry Skin

Dryness of the skin is caused primarily by the absence of oils on the skin's surface. The glands of people with ED produce too little oil. Dry palms and soles crack and bleed. The skin at the fingertips may be thickened and susceptible to scaling and fissuring. Many people affected by ED have a severe form of red, scaly and itchy dry skin, eczema, and bruise easily.

Eye Infections/Blocked Tear Ducts

There are many eye problems experienced by individuals with ED. Abrasion of the cornea may be caused by eyelashes which grow in an abnormal direction (dystichiasis). Tears that normally lubricate the eyes consist of a watery component from the lacrimal gland, a mucous protein from cells in the conjunctiva and oil from the glands in the eyelids. A deficiency may occur in any one or all three parts. Inadequate tears will cause drying and result in abrasions, pain and photophobia. Infection of the eye causes red eyelids, red conjunctiva, pus and crusting of the eyelashes, and may be accompanied by photophobia. Many individuals have dry eyes, few or no tears caused by missing or block tear ducts.

Hair

The scalp hair may be absent, sparse, fine, lightly pigmented, or abnormal in texture. The hair may be fragile and unruly, sticking out in all directions and difficult to comb. The hair is dry because the oil glands are absent or poorly developed. Absent, sparse or thin fine hair causes emotional distress and may be the cause of bullying.

Nails

Many people with ED have nails that may be poorly developed, small, thick or thin, brittle and slow growing nails or fissured nails, discoloured, cracked, or ridged. The nails may become infected by fungus or yeast, and become thick, discoloured and have a bad odour.

Nasal Infections

Crusty and foul smelling congestion in the nasal passages is common which, when it clears, often leads to severe nosebleeds. This is caused by a lack of mucous glands leading to abnormal functions of the linings of the nose, sinuses, Eustachian tubes and throat

The foul smelling congestion in the child's nasal passages cause problems for their peers in that many of them will either comment on the smell and refuse to sit by him or play with him. This causes emotional

distress and would be easily avoided if they had help clearing their nasal passages throughout the day. If assistance is not given to help the child clear their nasal passages during the school day they will incur nasal infections which will raise their body temperature, cause other infections, have an impact on their speech, cause problems with their peers and upset them emotionally.

Nosebleeds can affect the child at any time of day or night and it can take a long time to stem the bleeding. At all times there has to be a facility to take them to the nearest A&E Hospital.

Chest Infections

Due to abnormal body fluids many children with this condition are prone to bronchitis, asthma and other respiratory problems, they must, therefore, be kept away from dusty and smoky environments.

The linings of the nose, larynx, trachea and lungs are moistened by various glands, some of which may be defective in ED and thereby cause respiratory problems.

They will sometimes have hoarseness of their voice due to laryngeal dryness, which also causes coughing and recurrent upper respiratory infections.

Muscle Weakness

The child may appear to be unable to sit still and their legs will continually fidget. They may have muscle weakness and often complains that their legs hurt. The difficulty with their muscles will happen in both the summer and winter months make walking very difficult.

Physical Appearance

There are some physical signs connected with ED such as very thin, sparse, unruly head hair, very little body hair (if any), sometimes no eyelashes and in many cases no eyebrows. There is often increased pigmentation around the eyes or on the elbows, palms and soles. The heavily pigmented skin around the eyes is wrinkled and may be either pale or dark, and that on the palms and soles may be thick. As the child's appearance is very different from normal children this causes them huge emotional distress and may be the cause of bullying.

Emotional Well-being

Due to the child's appearance, dental problems and hypohidrosis they will be bullied throughout their young life. It is important to maintain their confidence and the school can help tremendously by being aware of their needs.

Children with ED are often very bright children, but to maintain their academic level they must be given the support required.

Summary of the need for a Carer

The child must not be allowed to get warm as their concentration will begin to wane immediately. They must be closely monitored during any IT work carried out in the IT room, PE and games, and appropriate cooling action taken.

As a consequence of the above aspects of the child's condition they need constant monitoring with regard to the amount of clothes they are wearing, encouragement to wear clothes and encouragement to remove clothes when they start becoming hot and the application of wet clothing, sprays, or fans to cool them.

They also need assistance and constant monitoring at all times with regards to meals and drinks to prevent choking.

A Carer would enable the child to maximise their education by meeting all their medical needs. A Carer would administer all medication, apply creams and eye drops, change their clothing and keep them cool throughout the day or warm depending on the temperature.

The child's temperature must be monitored from the moment they enter school to the moment they go home. They must not be allowed to get warm as their concentration will begin to wane immediately.





When the child becomes warm or cold in school their concentration will be lowered and they may not realise homework has been set. A Carer will be able to liaise with the child's parent at the end of each day with regard to any homework that has been set; the child cannot be relied upon to write things in a diary.

Due to the child's physical appearance, hearing and speech they will be bullied from time to time throughout his school life. A Carer would be able to notice anything brewing and be able to 'nip it in the bud'; they should be aware of the child's moods and notice if they suddenly became withdrawn.

A classroom teacher cannot, and should not, be expected to be constantly aware of the child's needs hence their need for a Carer. Equally the child cannot be relied upon to inform a teacher of his needs.

There are many times when the child may be kept off school or sent home from school due to lethargy; with a Carer in school this would not happen and the child's parent would feel confident sending them to school knowing there is someone to keep a close eye on their child and deal with any problems that may arise.

Individual Education Plan for (Example content)

 <p>Target</p>	 <p>How?</p>	 <p>Equipment</p>	 <p>Review of success</p>
<p>Jack is to be responsible for getting his own drink every morning and afternoon</p>	<p>Have a visual prompt or bottle on desk in the morning which Jack puts ready before he goes home from school</p>	<p>Visual prompt or drink bottle</p>	
<p>Jack is to check the thermometer regularly and to switch fan on when required</p>	<p>Thermometer placed on or near Jack's desk so he can check it easily</p>	<p>Thermometer, fan</p>	
<p>Jack to be responsible for his hat</p>	<p>Jack to wet his hat to wear when hot</p>	<p>Hat, water spray</p>	

Learning

How good am I at learning things at school?

Brilliant 

Really bad

How much do I want to get better?

A lot 

Not at all


Do I think I can get better at learning?

Yes 


No

Behaviour

How well do I behave at school?

Brilliant  Really bad

A How much do I want to change my behaviour?

A lot  Not at all

Do I think I can change my behaviour?

Yes  No

Pupil view	Parent view
<p>Good at?</p> <p>Not so good at?</p> <p>Favourite activity:</p> <p>Don't like?</p> <p>Friends?</p> <p>Like doing at home?</p> <p>Worried about?</p> <p>Get better at?</p>	

Teacher view

Name:

COP stage:

IEP number:

Date:

IEP agreed by:

Pupil:

Parent / Carer:

Teacher:

SENCO: